2026

STATE OF COLORADO

1876

SENATE JOINT RESOLUTION 26-014

BY SENATOR(S) Kipp and Simpson, Amabile, Baisley, Ball, Bridges, Bright, Carson, Catlin, Cutter, Danielson, Exum, Gonzales J., Hinrichsen, Jodeh, Kirkmeyer, Kolker, Lindstedt, Liston, Marchman, Mullica, Pelton B., Pelton R., Roberts, Rodriguez, Snyder, Sullivan, Wallace, Weissman, Zamora Wilson, Coleman;
also REPRESENTATIVE(S) Garcia and Johnson, Bacon, Barron, Boesenecker, Bradfield, Bradley, Brooks, Brown, Caldwell, Camacho, Carter, Clifford, DeGraaf, Duran, English, Espenoza, Flanell, Froelich, Garcia Sander, Gilchrist, Goldstein, Gonzalez R., Hamrick, Hartsook, Jackson, Joseph, Keltie, Lieder, Lindsay, Lukens, Mabrey, Marshall, Martinez, Mauro, McCormick, Nguyen, Paschal, Phillips, Ricks, Rutinel, Rydin, Sirota, Slaugh, Smith, Soper, Stewart K., Stewart R., Story, Suckla, Taggart, Titone, Valdez, Velasco, Weinberg, Willford, Winter T., Woodrow, Woog, Zokaie, McCluskie.

CONCERNING THE DECLARATION OF FEBRUARY 28, 2026, AS RARE DISEASE DAY.

WHEREAS, Coloradans with rare diseases, and their families, friends, and caretakers, know the challenges they face every day, such as finding knowledgeable providers, obtaining appropriate treatments, and paying and traveling for care, and the many other ways in which life can be extra challenging because of a rare disease; and

WHEREAS, One in ten people and more than 500,000 Coloradans live with a rare disease; and

WHEREAS, According to the National Institutes of Health, there are more than 30 million Americans, nearly 10% of the country's population, living with a rare disease today; and

WHEREAS, An estimated 15 million children in the United States have a rare disease, and, sadly, 30% will not live to see their fifth birthday; and

WHEREAS, There are more than 10,000 rare diseases, which are defined as medical conditions affecting fewer than 200,000 Americans, and most of these conditions may affect only a few hundred individuals; and

WHEREAS, These rare diseases are often lifelong, and many are terminal; and

WHEREAS, Most rare diseases are genetic or have a genetic component; no individual or family is immune from a rare disease; and

WHEREAS, Direct medical costs for people with rare diseases are three to five times higher than those for people with nonrare diseases; each year the costs amount to an estimated $400 billion nationwide and $12 billion in Colorado; and

WHEREAS, Fewer than 5% of the known 10,000 rare diseases have an FDA-approved treatment; and

WHEREAS, In 1983, the National Organization for Rare Disorders pioneered the passage of the federal "Orphan Drug Act", the world's first law incentivizing drug development for rare diseases by offering market exclusivity and tax credits; and

WHEREAS, The zebra is the official mascot for rare disease patients because, historically, medical professionals were taught that when they "hear hoofbeats", they should not expect to see a zebra and should instead look for the more common answer, a horse; and

WHEREAS, Today, we know that one in ten Americans is like a "zebra", living with a rare condition; it is not always obvious to recognize or diagnose a person with a rare disease, and, as a result, this can cause a delay in care and can often negatively impact a person's quality of life or life expectancy; and

WHEREAS, This Rare Disease Day, special events and activities are planned for February 27th and 28th, including lighting up Denver's City and County Building; additionally, individuals and families affected by rare diseases will be sharing their stories on social media, radio, and TV; in newspaper interviews; and at community events; and

WHEREAS, We see our constituents with these conditions and acknowledge the need for better understanding, the need for access to care, and the financial impact on families; and

WHEREAS, We also see that these families, despite the challenges, live their lives with optimism, hope for the future, courage, kindness for others, and, most of all, acceptance that this is, through no fault of their own, the life that they have been granted; now, therefore,

Be It Resolved by the Senate of the Seventy-fifth General Assembly of the State of Colorado, the House of Representatives concurring herein:

That we, the members of the Colorado General Assembly:

(1) Declare February 28, 2026, to be Rare Disease Day in Colorado to help raise awareness of rare diseases within Colorado;

(2) "Show our stripes" in solidarity with our community of individual "zebras" living with a rare disease;

(3) Recognize and support all of these individuals on this Rare Disease Day, in 2026 and every day;

(4) Salute these individuals for all that it means to live with a rare disease and the humanity that they show in so doing; and

(5) On this day, as we recognize Rare Disease Day around the country, take a moment to appreciate the more than 500,000 Coloradans, and the more than 30 million Americans, who live with a rare disease today.

Be it Further Resolved, That copies of this Joint Resolution be sent to the members of the Colorado Rare Disease Advisory Council.

James Rashad Coleman Sr.
PRESIDENT OF
THE SENATE

Julie McCluskie
SPEAKER OF THE HOUSE
OF REPRESENTATIVES

Esther van Mourik
SECRETARY OF
THE SENATE

Vanessa Reilly
CHIEF CLERK OF THE HOUSE
OF REPRESENTATIVES